

**Independent Review of the Work of the
Specialized Pediatric Services Review Committee (SPSRC)**

Submitted to the Minister of Health & Long-Term Care

by

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July 15, 2002

LETTER OF SUBMISSION

July 15, 2002

The Honourable Tony Clement
Minister of Health and Long-Term Care
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Dear Minister:

Enclosed you will find my brief report outlining the results of my independent review examining the work of the *Specialized Pediatric Services Review Committee* (SPSRC).

In accordance with the mandate provided, my review focused on the process, issues and recommendations of the SPSRC. The report includes my observations on these issues as well as additional recommendations to achieve a coordinated and comprehensive provincial program for specialized pediatric services and pediatric cardiac surgery in this province. For the most part, my recommendations support the work and recommendations of the SPSRC.

I agree with the SPSRC that a clear and final decision must be made on the future provision of tertiary pediatric cardiac surgery in this province. The ongoing debate with respect to the future consolidation of pediatric cardiac surgery has over-shadowed discussions and clouded the importance of the broader issues that need to be addressed to build a single provincial pediatric services system that will best serve the interests of children now and in the future. Moving this agenda forward requires that the roles and mandates of key players involved in pediatric cardiac care be clearly defined.

The reality today, however, is that the provision of tertiary pediatric cardiac surgery is evolving. Demographic changes as well as changing demands and practice patterns have impacted on the need for and demand on these services. Continued changes in these areas will continue to impact on the delivery of these services and consequently decisions must be made with a view to this. In the future, ongoing adjustments to the provincial pediatric system, including pediatric surgery, must be based on objective information gathered through a provincial data bank and completely agreed to by the centres involved.

.../continued

I hope that my findings and recommendations will be of assistance to you. I want to emphasize that this is an extremely difficult issue to address. I also recognize that regardless of the decision taken, there will always be a group of stakeholders and segments of the general population that will not be fully satisfied. At the same time, I believe we have an opportunity before us to build a high-quality system of specialized care in this province with strong roles for all regional pediatric centres and closer working relationships among them to build a true single specialized pediatric services system of care in Ontario.

Best wishes for success in resolving this very challenging problem.

Respectfully submitted,

Wilbert J. Keon, M.D.

Definitions and Acronyms Relevant to this Report

Pediatric care: Health care to patients less than 18 years.

Pediatric specialized care: Treatments or health services focused on neonates, infants, children and youth with a particular disease or group of disorders who require a multidisciplinary professional team often in addition to access to specialized equipment and facilities.

AHSCs	Academic Health Science Centres
CHEO	Children's Hospital of Eastern Ontario (Ottawa)
CHWO	Children's Hospital of Western Ontario (London)
CIHI	Canadian Institute for Health Information
HSC	Hospital for Sick Children (Toronto)
HSRC	Health Services Restructuring Commission
MoHLTC	Ministry of Health and Long-Term Care
PCCN	Pediatric Cardiac Care Network
SPCC	Specialized Pediatric Coordinating Council
SPSRC	Specialized Pediatric Services Review Committee

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1. Introduction

On May 29, 2002, I was requested by the Minister of Health and Long-Term Care, the Honourable Tony Clement, to undertake an independent review to examine the work of the Specialized Pediatric Services Review Committee (SPSRC):

*"You have been appointed to [the] task of providing an independent review of the committee's work and its recommendations... You have been asked to conduct a review of the process of the SPSRC, including the set of recommendations specific to tertiary pediatric cardiac surgery and the development of a provincial system of care for pediatric cardiology."*¹

It is important to emphasize that my task was not to undertake another review of the issue of specialized pediatric services in Ontario rather, to review the work and findings of the SPSRC. This report summarizes the findings of my review that focused specifically on issues related to the process and recommendations arising from the work of the SPSRC.

I believe that the SPSRC produced an excellent report. The report was based on a thorough review of the issues concerning the future delivery of specialized pediatric services. The SPSRC's recommendations should be supported. However, the SPSRC did not provide an implementation plan that lays out what is required to build an overall system for specialized pediatric services, including pediatric cardiac surgery. I believe that a clear implementation plan is a critical prerequisite required to implement recommendations in the SPSRC's report to ensure that we proceed with building a single pediatric provincial system of care for the future delivery of specialized pediatric services with strong regional centres working more closely together. Creation of a single pediatric provincial system will help to ensure that:

- We can provide the best quality of care for children,
- We develop a system that values and fosters the roles each regional provider plays in the provision of care within a single system,
- We strengthen research collaboration and linkages to meet new challenges and respond to growing international competition in the research sector,
- We are prepared to respond to the growing pressures and challenges to educate and recruit health professionals/providers who deliver services and develop stronger linkages between them.

Therefore, before implementing the SPSRC's recommendations and particularly those related to the consolidation of pediatric cardiac surgery, I believe that key steps must be undertaken to put in place the foundation and the processes for a provincial system that will ensure appropriate safeguards are in place to support a smooth transition.

¹ Personal correspondence to W.J. Keon from Tony Clement, Minister of Health and Long-Term Care dated May 29, 2002.

It is important to emphasize that the recommendations in my report build on the previous studies that have been undertaken on this issue and provide clear steps for establishing a provincial system that will maximize regional strengths and build on the centre of excellence that exists at The Hospital for Sick Children (HSC). My recommendations address several components sequentially to ensure that key elements of the provincial system are in place before changes in service delivery (related particularly to changes in pediatric cardiac surgery at CHEO) are implemented.

Notwithstanding the success of the current program at CHEO, my support for the SPSRC's recommendation to consolidate pediatric cardiac surgery services at HSC reflects the reality that the overall number of pediatric cardiac surgeries in the province is declining with indications that this trend will continue for some time. This trend has already impacted on the overall activity levels at CHEO and HSC, and is likely to continue to do so in the future. My support for consolidating pediatric cardiac surgery is contingent, however, on there being a clear implementation plan that includes the necessary mechanisms and processes required to avoid disruption and destabilization during a period of transition, and ensure continued access to the best quality of care for children in the short and longer term.

My recommendations focus on the need to develop a comprehensive cardiac care program in Ontario, with clear and defined roles for each of the regional players. It also focuses on ensuring that key activities are undertaken before pediatric cardiac surgery is consolidated at HSC. The recommendations address the following elements:

Step 1: Establish a Specialized Pediatric Coordinating Council, as recommended by the SPSRC.

Step 2: Establish a provincial Pediatric Cardiac Care Network (PCCN) to co-ordinate and provide advice on the provision of pediatric services across the province with clear responsibility for developing and maintaining a centralized pediatric cardiac database to provide consistent, reliable and timely information on the quality of and accessibility to pediatric cardiac services in this province.

Step 3: Develop an implementation plan and processes to address issues related to the consolidation of pediatric cardiac surgery services at HSC. This is a critical and necessary step to be undertaken by CHEO, HSC, the MoHLTC and other regional centres, as appropriate, to ensure that concerns about accessibility to HSC by residents from other parts of Ontario are addressed prior to consolidation, avoid disruption and ensure an orderly transition of services.

Step 4: Proceed with implementation of the consolidation of pediatric cardiac surgery at HSC in conjunction with the need to clarify the roles and scope of service delivery to be provided at the other regional pediatric centres including the north.

2. Process for Independent Review

2.1 *Timeframe*

While the original intent was to complete my review within a two-week period (concluding June 14, 2002) it became apparent early in the process that a brief extension would be required to allow me to consult fully with a broader range of individuals/organizations than initially anticipated. As a result, the timeframe for this review was extended to July 15, 2002.

2.3 *Interviews/Meetings*

During my review, I conducted a number of meetings and/or discussions with several representatives. The purpose of these meetings/discussions was to establish contact with each of the key parties to:

- Acquire an understanding of the process used by the SPSRC to reach their decisions.
- Gain a clearer understanding of the basis upon which the SPSRC arrived at its recommendations.
- Determine what, if any additional issues resulting from the SPSRC process and report, needed to be addressed to resolve the issues facing specialized pediatric service delivery in the province.

The dates and names of participants at meetings conducted as part of this review can be found in Attachment A.

3. Highlights of the SPSRC Recommendations

The SPSRC report built on the considerable work undertaken on this topic; in particular, the provincial review of specialized pediatric services undertaken by the Health Services Restructuring Commission (HSRC) in 1997-98. The SPSRC also considered the recent studies undertaken in other jurisdictions concerning the consolidation of pediatric cardiac surgery (e.g., Winnipeg, Manitoba and Bristol, England).

Consideration of updated province-wide information, national/international trends, and current research led the SPSRC to make the following recommendations for the delivery of pediatric cardiac surgery:

- (1) To ensure best outcomes, a coordinated system of tertiary pediatric services is required in the province and includes both surgical and medical services. The five academic centres should build on the experience of the SPSRC and commit to closer, collaborative relationships to effect this change and ensure access to specialized care.
- (2) To centralize tertiary pediatric cardiac surgery on one site with a targeted implementation date of April 2003. The recommended site is The Hospital for Sick Children. In addition, given that current medical practice recommends on-site surgical back-up for interventional catheterization procedures, pediatric cardiology using these methods, including immediate post-operative intensive care, centralize these services at the same site, unless otherwise agreed to by members of the pediatric cardiac network (a medical forum proposed by Chairs/Chiefs not yet established).

- (3) The five Academic Health Science Centres (AHSCs) will collaborate with the Ministry of Health and Long-Term Care to make further recommendations on the provision of supports for families traveling greater distances for tertiary pediatric cardiac surgery.
- (4) To support the tertiary pediatric surgery program transfer and consolidation of these services on one site, a regional model for pediatric intensive care, including pre-operative and post-operative care must be developed.
- (5) Pediatric cardiac specialists in a tertiary pediatric settings should undertake tertiary pediatric cardiac surgery involving neonates and the 0 to 14 age groups.
- (6) The single site must be capable of providing service in both Official Languages.

A number of recommendations concerning the delivery of transplantation services were also articulated in the report. I did not review these in depth but found that there is strong support for them among the representatives who participated in the SPSRC process.

In summary:

Given the implications arising from national/international trends, declining volumes in cardiac surgery, changes in cardiac treatment, and the need to design a future provincial system to co-ordinate and plan tertiary pediatric services, the SPSRC supported establishment of a Specialized Pediatric Co-ordinating Council (SPCC) for hospital-based specialized pediatric services. They also recommended consolidation of tertiary pediatric cardiac surgery at a single site as an integral component in the design of a renewed provincial system.

4. Observations Resulting from Independent Review

Having reviewed the process undertaken by the SPSRC, as well as its report and recommendations, and having consulted with key stakeholders involved in the provision of tertiary pediatric services in the province, my observations are as follows:

4.1 *Overall observations on the review of specialized pediatric services in Ontario*

- There have been three reviews undertaken on the issue of specialized pediatric services in Ontario within a short period of time. Two reviews were undertaken by the HSRC and one by the SPSRC.

March – December 1997: In March 1997, the HSRC established a Provincial Pediatric Task Force (PPTF) to address the issue of program consolidation and co-ordination of service delivery related to low volume tertiary and quaternary pediatric services. The decision to establish the PPTF was precipitated by the HSRC's review of health services in major centres across the province. The mandate of the PPTF was to recommend opportunities for consolidating tertiary and quaternary services into a single delivery system and/or to identify those programs with sufficient volumes to warrant multiple regional delivery sites.

June – September 1998: The HSRC appointed an Independent Review Panel comprised of three physicians from outside Ontario. The Panel was asked to review the assumptions used by the PPTF to reach their decisions, and to comment on their findings and conclusions.

November 2001 – March 2002: Established by the Minister of Health and Long-Term Care on November 5, 2001, the SPSRC was mandated to undertake a review of specialized pediatric services in the province.

In summary:

All of the review processes undertaken in recent years concluded that a greater degree of collaboration and consolidation are key to the provision of high quality tertiary and quaternary pediatric services (as they are for many other specialized health care services).

4.2 Observations on the SPSRC process and recommendations

- The SPSRC conducted a good process that appropriately involved representation of key stakeholders in the field of pediatrics in this province. The review built on the considerable work done in the past on the issue. The decision-making of the group was informed by the best quality data available and the most recent research on issues pertaining to consolidation and, in particular, the relationship between volume/critical mass and patient outcomes.
- The report developed by the SPSRC reflects the 'consensus' reached by the group with respect to the recommendations and conclusions included in the report.

In summary:

The SPSRC report is an excellent report that was developed by a well-qualified and well-respected group of people. The Committee conducted a comprehensive review of the issue concerning the future delivery of specialized pediatric services, including pediatric cardiac surgery in Ontario, and relied upon the best quality data available to support them in their decision-making.

4.3 Observations on trends in the provision of pediatric cardiac surgery

- There is a clear recognition among the key players of the importance of addressing pediatric cardiac surgery as the first priority. This belief is based on the understanding that resolution of this issue would also provide for the creation of an ongoing framework for collaboration among the five pediatric AHSCs and northern centres in the provision of specialized pediatric services.
- There is general agreement on the need for a clear and final decision on the provision of pediatric cardiac surgery within the context of what is in the best interest of children and what is needed to build a co-ordinated and comprehensive quality provincial system of care for children.

- There is a need to acknowledge that this is an extremely difficult issue to address and regardless of the decision taken there will always be a group of stakeholders and segments of the general population that will not be fully satisfied.
- The provision of pediatric cardiac surgery is evolving. Changing demands and practice patterns have impacted on the need for and demand on these services. Continued changes in the field will continue to impact on the delivery of these services and consequently, decisions must be made with a view to this.
- The most significant conclusion arising from a review of trends is that the total number of pediatric cardiac surgery cases has been decreasing with the trend expected to continue in the future. The two key factors contributing to the overall decrease in pediatric cardiac surgery volumes are:
 1. **Changing Practice Patterns:** There has been an overall decline in the total number of cardiac surgery cases arising from significant changes in practice patterns. Changes in practice patterns relate primarily to an increasing trend toward the use of interventional catheterization (in place of cardiac surgery procedures), and multiple interventions being undertaken during a single operation, thereby reducing (or eliminating) the need for repeat surgery. As a result of changing practice patterns, pediatric cardiac procedures are being done in younger children.
 2. **Demographics:** The population between 0 and 14, which consists of approximately 90 per cent of pediatric cardiac surgery cases, is expected to decline at a rate of 0.5 per cent per year over the next ten years.

In summary:

- Current trends point clearly to a decline in pediatric cardiac surgery volumes resulting from changing practice patterns and decreasing demographics. There is agreement that as treatment modalities continue to evolve, demand for cardiac surgery in the pediatric population will continue to decline.
- A final decision on the provision of pediatric cardiac surgery must be made within the context of its role and contribution to building a co-ordinated provincial system of specialized care for children. The role of the regional centres involved in pediatric cardiac care must be defined as part of building this co-ordinated system of specialized care. Further delay in decision-making with respect to the provision of pediatric cardiac services in Ontario will continue to 'destabilize' and further fragment the system.

4.4 Observations on data analysis

- My review also included an analysis of the base data used by the SPSRC to reach their conclusions. My fundamental objective here was to confirm the 'reasonableness' of the analysis undertaken by the SPSRC and to identify issues with the data used in the decision-making process.
- There is ongoing debate on the limitations of existing data to measure levels and type of activity and outcome. The SPSRC was able to agree on an approach to use CIHI data sources for their review.

Concerns with the CIHI data have centered on the limited level of detail that it provides regarding the type of cardiac surgery interventions. Other databases available from HSC, CHEO and CHWO were also considered by the SPSRC. These data provide more details on the type of cardiac surgical procedures. Recent debate has also focused on the interpretation of mortality rates that have been reported by hospitals through the CIHI data system for pediatric cardiac surgery. There is lack of agreement on the reporting of mortality rates when multiple diagnosis are involved. Therefore, in the absence of a comprehensive provincial data base and standardized approach a proper analysis and comparison of mortality rates across pediatric cardiac surgery institutions are not possible.

- Notwithstanding the debate, the CIHI data provides sufficient detail to assess levels of pediatric cardiac activity and trends over time. Additional data provided to me by each of the three centres (London, Ottawa, Toronto) is consistent with CIHI data in terms of levels of activity for the provincial pediatric population.

In summary:

- The activity data indicate that there is a clear difference in caseload, both in terms of volumes and type of procedures performed, among the centres.
- There is an urgent need to establish a standardized provincial cardiac database to address both activity and outcome related to pediatric cardiac surgery. The provincial database should be capable of producing reliable data upon which planning and program management decisions can be based. Issues with respect to different data collection and analysis methods arising from the different databases for pediatric cardiac surgery have complicated and prolonged discussions/decisions on the issue of consolidation. A standardized database similar to the adult database operated and managed by the Cardiac Care Network (CCN) would go a long way to provide a comprehensive basis for planning and monitoring service access and quality (including establishment of benchmarks). *(Specific recommendations related to this issue are provided in the conclusions and recommendations section of the report.)*

5. Implications of a Single Site Model for Pediatric Cardiac Surgery

Observations on the current situation:

- As noted earlier, the SPSRC recommended the consolidation of tertiary pediatric cardiac surgery on one site with a targeted implementation date of April 2003. The SPSRC's recommended site is The Hospital for Sick Children. The implications of this recommendation is that after April 2003, CHEO would no longer provide pediatric cardiac surgery
- While there was consensus among members of the SPSRC for consolidation of pediatric cardiac surgery on a single site there was also recognition that this change can not happen overnight. In particular, concerns relate to HSC's capacity to accommodate 100 per cent of the provincial pediatric cardiac surgery volumes now. The HSC has advised me that it is taking steps to ensure availability of necessary facilities, staff resources and clinical expertise.

- At the same time, it is important to recognize that strong linkages currently exist between Ottawa/Toronto (and previously London/Toronto) with respect to case selection of cardiac surgery cases. In fact, current experience, trends and caseload characteristics point clearly in the direction of a natural evolution toward development of a single centre for pediatric cardiac surgery.
- Since the release of the SPSRC report in May 2002, there has been significant debate and expression of concerns, particularly with respect to CHEO's and the CHWO's role in pediatric cardiac surgery.
- With regards to CHEO's role in pediatric cardiac surgery, the issues that have been raised with me relate to the following:
 1. Accessibility: There are significant concerns that accessibility to tertiary cardiac surgery will be affected if the service is no longer available at CHEO. Issues include:
 - Lack of sufficient capacity at the HSC to accommodate the additional volumes from the areas served by CHEO;
 - Lack of capacity of the air ambulance service in Eastern Ontario to transport critically ill cardiac surgical patients.²
 - Requirement for bilingual services (Note: the SPSRC noted that both CHEO and HSC are designated to provide services under the French Language Services Act).
 2. Viability of CHEO's cardiac program: CHEO is concerned that if it no longer provides pediatric cardiac surgery, there will be repercussions on numerous other services, including retention and recruitment of qualified personnel thereby placing the provision of other pediatric programs at risk.
- With regards to CHWO, concerns and issues that have been brought to my attention have focused primarily on two areas:
 1. The potential for re-establishing pediatric cardiac surgery in London.
 2. "Fall out" resulting from decision to close pediatric cardiac surgical program: Immediate action to address the impact of the closure of the pediatric cardiac surgical program. A key concern is CHWO's ability to continue to function as a provider of specialized pediatric care to children in southwestern Ontario, and to provide specialized pediatric programs, particularly its critical care and cardiology services - and associated academic programs and medical schools.

In summary:

- **Notwithstanding these issues, I believe that the arguments and rationale by the SPSRC in support of a one-site model for pediatric cardiac surgery are difficult to refute. The decision of**

² Representations have noted that the planning of training and staffing or pediatric transport teams is presently taking place through the recently established Ontario Pediatric Intensive Care Network. This Network includes representatives of the five Academic Health Science Centres and is expected to make recommendation to the MoHLTC.

the SPSRC was based on the assessment of various criteria, including quality of care and accessibility.

- The characteristics of the current trends and case load selection process that is undertaken between HSC and CHEO point clearly in the direction of a "natural evolution" toward development of a single centre for pediatric cardiac surgery. In fact, based on current trends (which indicate declining pediatric cardiac surgical volumes) the potential exists for the volumes at CHEO to decrease to a level where the cardiac surgical program can no longer be sustained.
- At the same time, however, the issues raised with regards to the potential transfer of pediatric cardiac surgery from CHEO to HSC and the impact of the recent transfer of CHWO's cardiac surgical program to the HSC cannot be ignored. Although the SPSRC has already provided recommendations to address these concerns, I believe that several key implementation steps need to be undertaken before pediatric cardiac surgery services can be consolidated on one site, and also to address issues at CHWO.

6. Conclusions and Recommendations Arising from Review

- The recommendations of the SPSRC should be supported. I strongly share their view that a **provincial system-wide approach** is needed to address the provision of specialized pediatric services, including cardiac surgery. The recommendations made by the SPSRC reflect the reality that the provision of tertiary pediatric cardiac surgery is evolving. Changing demands and practice patterns accompanied by demographic changes have impacted on the need for and demand on these services. Continued changes in these areas will continue to impact on the delivery of these services and consequently decisions must be made with a view to this.
- However, the SPSRC report did not provide an implementation plan for its recommendations with a view to the overall provincial context. My recommendations build on the previous studies and the SPSRC's recommendations and provide clear implementation steps for establishing a provincial system that maximizes regional strengths and builds on the centre of excellence that exists at HSC.
- My recommendations address several components that must be undertaken to ensure that key elements of the provincial system are in place before changes in service delivery are implemented, including the consolidation of pediatric cardiac surgery at HSC. This should provide the necessary safeguards and avoid disruption and destabilization during a period of transition. In particular, my recommendations focus on the need for development of a comprehensive pediatric cardiac care program in Ontario, with defined roles for each of the regional players. The program would consist of the following elements:

Step 1: Establish a Specialized Pediatric Coordinating Council, as recommended by the SPSRC.

Step 2: Establish a provincial Pediatric Cardiac Care Network (PCCN) to co-ordinate and provide advice on the provision of pediatric services across the province. A key responsibility of the PCCN should be to develop and maintain a centralized pediatric cardiac database that will provide consistent, reliable and timely information on the quality of and

accessibility to pediatric cardiac services in the province.

Step 3: Develop an implementation plan and processes that address issues related to and support the consolidation of pediatric cardiac surgery services at HSC. This is a critical and necessary step to be undertaken by CHEO, HSC, the MoHLTC and other regional centres, as appropriate, through the PCCN to ensure program access and that CHEO, CHWO and other regional centres will continue to provide viable critical and cardiac care programs.

Step 4: Proceed with implementation of the consolidation of pediatric cardiac surgery at HSC in conjunction with the need to clarify the roles and scope of service delivery to be provided at the other regional pediatric centres including the north.

RECOMMENDATION 1: Establishment of a Specialized Pediatric Co-ordinating Council (SPCC)

The Minister of Health and Long-Term Care establish the Specialized Pediatric Coordinating Council (SPCC) as recommended by the SPSRC. The SPCC would be advisory to the Minister of Health and Long-Term Care and would provide an ongoing focus for the provision of specialized services for children.

The mandate of the SPCC would be to enhance the delivery of specialized pediatric health care services across Ontario through development of a provincial network based on:

- Enhanced (and clarified) roles for regional centres, including the development of a regional model for pediatric intensive care, including pre-operative and post-operative care.
- Consolidation of 'selected' specialized services where warranted,
- Strengthening of the provincial transport system to support regional system development,
- and
- Development of an integrated single provincial system of care based on best practice.

Membership should include representatives of the five AHSCs as well as northern centres in Thunder Bay and Sudbury.

Rationale:

- Any (and all) changes made with respect to specialized pediatric services in Ontario must be made within the context of designing a true *provincial system* for the future that is sustainable and anchored in quality patient outcomes. Future changes are also predicated on the need to establish a provincial system capable of overseeing, reviewing and monitoring outcomes of all pediatric specialized services. The establishment of a focal point will facilitate collaborative planning across regions and help to foster development of academic programs, clinical activity and research in the best interests of all children in the province.
- Building a provincial system will also demand changes that will build upon the strengths of each pediatric regional centre in serving the secondary/tertiary pediatric needs of their region. Confirmation and enhancement of the geographic catchment area and role/scope of services for each of the

regional centres is needed and should be *one of the first tasks* addressed by the SPCC. To make the provincial system work, the cooperative and seamless program to program relationship(s) must be strengthened between the AHSCs in London, Ottawa, Hamilton and Kingston with HSC. Much has already been achieved in connecting some centres. Excellent working relationships already exist between members of cardiology/cardiovascular surgery programs between HSC and other centres. However, there is a need to formalize and enhance relationships for all aspects of specialized pediatric programs.

- Expertise of a skilled transport team proficient in the safe care and transport of the neonatal and pediatric population are required to ensure acute, unstable pre-operative and post-operative patients will be appropriately moved throughout the province. Members of the provincial air ambulance program are also key to the successful transfer of these patients. While these flight paramedics are highly skilled, they may lack experience with the paediatric population. Hence, the collaboration between air ambulance personnel and the neonatal/paediatric transport teams are needed to optimize patient outcomes and ensure that the highest quality care is provided.
- There is broad support among the AHSCs for establishment of a Specialized Pediatric Co-ordinating Council.

Features of a Provincial Network of Specialized Pediatric Services

Vision

Academic health science centres and northern communities working together to improve the accessibility, quality, and efficiency of health services for infants, children and youth through building of strong, functionally-integrated regional models [of critical care] of people, services, and organizations across the province with consolidation of low volume/highly specialized services at selected sites, where appropriate.

Goals

- To facilitate access to services closer to home by defining the geographic catchment area and scope of services for each regional centre and redirecting and/or repatriating patients to these centres, as appropriate.
- To consolidate critical mass of low volume and/or highly specialized services to optimize patient outcomes.
- To clarify the scope of services that can be provided at each regional centre and to what degree caseload can be redistributed.

Characteristics

From	To
An individual regional focus with uncertainty concerning roles with respect to pediatric critical care.	All regions working more closely together with defined parameters of practice for supporting the development of regional models of pediatric critical care.
Facility-based standards of care.	Common care standards (practice guidelines) across a provincial pediatric network.
Inconsistent bed and resource utilization.	Improved access and resource optimization.
Fragmented services.	Stronger regional/provincial system with continuity of care.
Human resource inconsistencies and shortages.	Pooling of specialized resources, expertise and ideas.
Lack of benchmarks	Identification of provincial benchmarks.
Random and varied use of data collection and analysis.	Consistent data collection and analysis.

Recommendation 2: Establishment of a provincial Pediatric Cardiac Care Network (PCCN)

Endorse the need to develop a coordinated system for the delivery of pediatric cardiac services through establishment of a *Pediatric Cardiac Care Network (PCCN)*. The Minister of Health and Long-Term Care should establish the Network based on representation from all of Ontario's academic health science centres as well as representation from the north. The Network would be accountable to the Specialized Pediatric Co-ordinating Council and be supported in its work to:

- **Establish and manage a common database to monitor pediatric cardiac activity at each site including waiting times and outcome indicators related to cardiac surgery, interventional and diagnostic catheterization, as well as cardiology clinic activity.³ The PCCN should report annually on activity and outcome. Strong consideration should be given to adopting and enhancing the cardiac data base system in place at the HSC.**
- **Examine and make recommendations as to the specific roles of each regional network partner with a view to determining what additional roles each of the centres can provide particularly with respect to interventional pediatric cardiology procedures. One of the significant issue arising from the consolidation of cardiac surgery relates to the impact on invasive cardiology. The SPSRC recommended the consolidation of interventional cardiology along with pediatric cardiac surgery, based on current medical practices. In light of experiences in other jurisdictions and the recent report by Ontario's Cardiac Care Network related to the adult population, the PCCN should examine and provide advice on whether some interventional cardiology procedures can safely be provided in pediatric cardiology centres that do not have pediatric cardiac surgery back up.**
- **Explore opportunities to establish a shared electronic health record for patients. One option for doing this may be through the existing electronic child health network (eCHN) health information network platform.**

Rationale:

- **There is a need for a dedicated group representing the cardiac programs at the five pediatric academic health science centres and northern centres to oversee and advise on the development of a co-ordinated and seamless pediatric cardiac program for the province. The PCCN should be a partnership of pediatric cardiac care providers, pediatric academic health science centres and government. Its focus should be on ensuring appropriate quality and access to cardiac care by the pediatric population.**
- **Additional responsibilities of the PCCN should include the following:**
 - **To monitor the quality and outcomes of pediatric cardiac services and outcomes across the province and provide annual reports on activity and outcomes;**

³ Establishment of the database will also allow for dissemination of regular reports across the 'system', and provide reliable data upon which information can be extracted to review and make recommendations on quality indicators, service volumes, outcomes, and access including waiting times and transport.

- To facilitate the development and dissemination of guidelines for cardiac services that will promote greater standardization and equity in service delivery across the province and ensure the timely uptake in adoption of 'best practices' in the field.
- To oversee the evolution of a co-ordinated provincial cardiac care program in Ontario within the context of designing a provincial 'system' of pediatric cardiac care.
- To further clarify the roles and responsibilities of each of the five academic health science centres (and the major regional centres in the north namely, Thunder Bay and Sudbury) with respect to cardiac assessment, treatment, and follow-up in the pediatric population.
- To determine the scope of services that can be provided at each regional centre and to what degree caseload can be redistributed.
- To oversee the consolidation of pediatric cardiac surgery centre at HSC, including resolution of accessibility and other issues, and ensure appropriate steps are taken to maintain access to care and service continuity during the transition period.

Recommendation # 3:

The recommendations that follow provide key implementation strategies and safeguards to strengthen the development of a regional model for pediatric care, including the development of a provincial program for pediatric cardiac surgery.

Recommendation 3.1 – Pediatric Cardiac Surgery: CHEO and HSC

The pediatric cardiac program at CHEO should remain open until the following have been addressed:

- **Strategies and implementation plans to ensure the maintenance of a strong regional pediatric cardiology program as part of a co-ordinated and seamless provincial program, including strategies for a regional model of pediatric critical care, to sustain local expertise and key academic programs, where appropriate.**
- **Strategies and initiatives to address potential access issues including,**
- **Availability of necessary space and resources capacity at HSC to accommodate additional volumes,**
- **Availability of appropriate capacity to transport critically ill pediatric patients,**
- **Confirmation of access to services in French at HSC;**
- **Development of, and where appropriate, strengthening of existing protocols to support strong relationship between CHEO and HSC to facilitate patient transfers and access; and**
- **Other issues related to accessibility to HSC's pediatric surgical programs.**

CHEO and HSC should continue to build on the current arrangements related to case selection and establish joint working committees to ensure appropriate access and quality of care during

the transition period as the system evolves toward one site.

Explore adjustments required to the transport system to consolidate pediatric cardiac surgery at HSC.⁴

The PCCN should develop a workplan including timelines for accomplishing these tasks.

Rationale:

- This recommendation is being made with a view these concerns and reflects the need for a managed approach to consolidation of paediatric cardiac surgery that will ensure the stability of the program at CHEO during a period of transition and continued access in the future to quality cardiac surgery program by children in Eastern Ontario and other regions that now rely on CHEO for services.
- This recommendation should not be viewed as a reflection on CHEO or its paediatric cardiac program. CHEO's paediatric surgical program is well regarded among the paediatric cardiology community. However, given current trends, the provision of paediatric cardiac surgery services is naturally evolving toward the development of a single centre. Based on current and expected trends, it is likely that within a period of time volumes at CHEO will decline to a level that will render its cardiac surgical program unsustainable.

Recommendation 3.2 – Regional Model for Pediatric cardiology and Intensive Care

As recommended by the SPSRC, strategies and implementation plans should be developed to ensure the maintenance of strong regional pediatric cardiology programs, with clear and well defined scope of service and regional responsibilities, as part of a coordinated and seamless provincial program, including strategies for a regional model of pediatric critical care. Development of a regional model for pediatric cardiac care must include pre-operative and post-operative care at all of the sites as well as any necessary changes to the transport system to ensure timely access for pediatric cardiac surgery and other specialized pediatric services.

Development and/or strengthening of existing protocols to support strong relationships between the regional centers and HSC to facilitate patient transfers and access including exploring adjustments required to the transport system to consolidate pediatric cardiac surgery at HSC.⁵

The SPCC should be asked to lead this task.

⁴ The model could build on the following proposed model:

- Cardiac patients < 2 years of age will be transported by team members from the existing HSC Acute Care Transport Service (ACTS) working in collaboration with members of the provincial air ambulance program. This team would retrieve patients requiring cardiovascular surgery from the referral hospitals across the province to HSC. Once stabilized in the early post-operative period, these patients will be retro-transferred for ongoing care to their tertiary referral centre closest to the family's home.
- Cardiac patients greater >2 years of age will be accompanied by the air ambulance paramedics and a physician from the Critical Care Program either from HSC or their referral Critical Care Programs.

⁵ The model could build on the following proposed model:

- Cardiac patients < 2 years of age will be transported by team members from the existing HSC Acute Care Transport Service (ACTS) working in collaboration with members of the provincial air ambulance program. This team would retrieve patients requiring cardiovascular surgery from the referral hospitals across the province to HSC. Once stabilized in the early post-operative period, these patients will be retro-transferred for ongoing care to their tertiary referral centre closest to the family's home.
- Cardiac patients greater >2 years of age will be accompanied by the air ambulance paramedics and a physician from the Critical Care Program either from HSC or their referral Critical Care Programs.

Rationale:

- This recommendation builds on the SPSRC's recommendations on the development of a regional model of pediatric care, and particularly pediatric intensive care. The pre and post operative patient management should continue to be provided by designated tertiary referral centres for each region (or catchment area) in Ontario. This model is well aligned and in keeping with the regionalized transfer process for high-risk maternal and newborn care in the province. Further, it facilitates the concept of regionalized care where appropriate care is provided closest to the family's home and also ensures the viability of each regional tertiary centre. However, a standardized structure and process for transporting paediatric and neonatal patients within Ontario are key to the success of a centralized program for pediatric cardiac surgery at HSC

Recommendation 3.3 – CHWO

- This recommendation deals specifically with the CHWO in London and is related to the impact of the recent closure of the cardiac surgery program on its pediatric critical care program.
- Immediate measures should be undertaken to address the impact of the CHWO of the loss of cardiac surgery on its critical care units including designation of CHWO as the preferred provider of critical care to children in southwest Ontario and other regions of the province as appropriate (e.g. Kitchener-Waterloo).⁶

Rationale:

- The recommendation that deals specifically with CHWO in London supports the recommendation of the SPSRC that the SPCC develop "regional models for pediatric critical care" while helping London maintain a critical mass of seriously ill patients to sustain local expertise and key academic programs. Without this designation, London's pediatric critical care unit and its associated inter hospital transport team are seriously threatened. Loss of these programs in the short-term will not only adversely impact upon the province's capacity to provide pediatric specialized care to Ontario's sickest children but also threaten the future of the University of Western Ontario's Department of Pediatrics and its associated pediatric critical care residency program. This latter residency program has been responsible for the education of many of Canada's pediatric critical care subspecialists and is one of the premier fellowship programs offered by the University of Western Ontario and supported by the Ministry of Health and Long-Term Care.

⁶ The decision concerning provision of services to those in the north (including Thunder Bay, Sault Ste. Marie and Sudbury) should be addressed as part of the initial work to be undertaken by the SPCC confirming catchment areas for all of the regional centres.

Attachment A: Summary of Consultations/Meetings

Representatives of the Hospital for Sick Children (HSC) - Dr. Alan Goldbloom, Executive Vice President and Chief Operating Officer - Mary Jo Haddad, Vice President, Medical Services - Dr. Hugh O'Brodovich, Pediatrician-in-Chief, Academic Chair, Pediatrics, University of Toronto - Dr. Andrew Redington, Head, Cardiology - Cathy Seguin, Vice President, Surgical Services - Dr. Glen Van Arsdell, Head, Cardiovascular Surgery - Dr. Bill Williams, Cardiac Surgeon (former head of cardiac surgery)
Representatives of the Ministry of Health & Long-Term Care (MoHLTC) - John King, ADM, Health Care Programs and SPSRC Co-Chair - Debbie Latter, Consultant, Health reform Implementation Team - Catherine Pepevnak, Hospital Consultant, Toronto Region - David Stolte, Director, Health Reform Implementation Team - Gail Ure, Executive Director, Health Care Programs and SPSRC Co-Chair
Representatives of the Children's Hospital of Eastern Ontario (CHEO) - Garry Cardiff, President and CEO, CHEO - Dr. Joe Reisman, Chief, Department of Paediatrics - Dr. Merv Letts, Chief, Department of Surgery - Dr. Simon Davidson, Chief of Staff - Dr. Robert Gow, Chief, Division of Cardiology - Dr. Gyaandeo Maharajh, Division of Cardiovascular Surgery - Dr. Jamie Hutchison, Head, Paediatric Critical Care
Representatives of the Hamilton Health Sciences (HHS) - Dr. Charlie Malcomson, Chief of Paeds - Dr. Peter Fitzgerald, Medical Director of the Children's Hospital - Dr. Mike Marcaccio, Chief of Surgery - Ms. Alida Bowman, Clinical Manager of Acute Paeds - Dr. Paul Kanter, Pediatric Cardiologist - Ron Sapsford, Executive Vice-President and COO. - Dr. John Watts, Academic Chair (A), Pediatrics at McMaster University
Representatives of London Health Sciences Centre (LHSC) - Tony Dagnone, President and CEO, London Health Sciences Centre - Dr. Tim Frewen, Chair and Chief of Pediatrics, University of Western Ontario
Representatives of Kingston General Hospital/Queen's University: Dr. Kimberly Dow, Academic Chair, Pediatrics, Queen's University
Northern Centres: - Ms. Vickie Kaminski, President and CEO, Sudbury Regional Hospital
Others: - Dr. James Young, Chief Coroner, Province of Ontario - Maureen Quigley, Facilitator, SPSRC